MODELING ELECTRONIC REPORTING PROJECT (MERP)

SUMMARY TECHNICAL REPORT

INFORMATION PROCESSING WITHIN THE VIRGINIA COMMONWEALTH UNIVERSITY MASSEY CANCER CENTER CANCER REGISTRY SYSTEM

November 15, 2004

Introduction

The Modeling Electronic Reporting Project (MERP) is an effort to understand and model the transformation of cancer registries from their current state towards one that takes advantage of the increasing availability of electronic medical records. This report is a summary of the information resources and operational procedures of one hospital-based cancer registry. The emphasis is on those resources and procedures that are most relevant to the MERP project's objectives. A more complete analysis of the hospital registry procedures is beyond the scope of this report. The information contained within is based on a site visit to the hospital and to the central registry, conversations with the individuals who play primary roles in the cancer registry processes, and documentation provided by the registry personnel.

Overview

The Massey Cancer Center (MCC) is part of the Virginia Commonwealth University Health System (VCUHS). MCC is a multidisciplinary group responsible for the collection of data related to the diagnosis and treatment of cancer patients. The VCUHS cancer registry is an American College of Surgeons Commission on Cancer-approved program. The MCC cancer registry accessions more than 1500 new patients annually. The registry provides information and data for purposes of certification, for research related to clinical trials, health services research and other research related to cancer epidemiology, cancer etiology and treatment.

Hospital Information Systems

VCUHS has recently converted its primary patient care software from the Eclipsys Medical Information System to the Cerner Millennium System, a modular suite of software applications. The applications include the PowerChart and PowerChartOffice patient clinical information applications, FirstNet and PharmNet applications for emergency room and pharmacy management, and the PathNet Laboratory Information System, used for Anatomic Pathology and Clinical Pathology Laboratory results. The PowerChart Enterprise Clinical Data Repository (CDR) provides a longitudinal view to all patient information within the Cerner system and functions as the hospital's electronic medical record (EMR).

The PathNet application suite has been in use since October of 1999, and the other applications were brought online in May 2004.

Inpatient registration, admission, discharge, and outpatient clinic scheduling, registration and discharge information is maintained through the IDX system which is interfaced to the Cerner system for data exchange. The IDX system also supports professional billing for physicians and other health care providers, and includes diagnosis, procedure and charge codes.

A separate billing system (PARS) is interfaced with the Cerner system and provides technical billing for hospital and clinic services. These billing files contain demographic, diagnosis, procedure (including drug administration), and charge codes.

In addition to these transactional-based systems, the hospital maintains a separate repository of patient registration and admission information and administrative accounting information known as the Decision Support (DS) system. The DS is populated on regular intervals with data from several hospital-based systems. It is updated daily with patient demographics, orders and admission/discharge/transfer information taken from the Cerner Millennium system, monthly with additional patient visit and discharge information from the PARS, IDX and General Ledger systems and annually from the Cost Accounting system. The DS provides a complete administrative view of all patient visits, inpatient and outpatient, including demographics, provider information, ICD-9 diagnosis and procedure codes, CPT codes, DRGs , charge codes, including detailed charges, and payor information.

Massey Cancer Center Information Systems

- Claims database

The Massey Cancer Center Information Systems (MCCIS) claims database is a locally-maintained relational database that is populated by extracting and restructuring information from the Decision Support System. On a quarterly basis, programs are executed within the DS to extract information on cancer patients. Hospital cancer patients are identified in two ways. The first is done by matching ICD-9 diagnosis codes to a pre-defined list of codes that are considered relevant to oncology. The second is done by matching discharge provider IDs that are associated with either Oncology or Hematology. These two queries produce a master list of patient accounts. This list is purged of duplicate records and is used to perform additional queries that extract information on all visits for each patient in the list.

To supplement the hospital patient claims information, the DS is queried for information pertaining to physician claims data. Cancer patients are identified in two ways. As with hospital patients, one approach is to compare primary and first secondary diagnosis codes to a list of pre-defined codes. The second approach is to determine if the “billing area”, a hospital-specific billing attribute, contains keywords that would be associated with a cancer patient. Currently the terms used for comparison are “Onc” and “Hanover Medical.”

The programs that query the DS produce several text files. These files are transferred electronically to another computer via FTP. The data in these files is then loaded into the MCCIS relational database and some post-processing occurs. Each quarter, when this process is run, the database is first purged of all existing data. The newly rebuilt database is then a snapshot of the current state of the Decision Support system. Five years worth of

data are maintained in the database and information going back to 1992 is available in an offline archive.

Pharmacy billing information is also maintained in the MCCIS claims database, providing a more detailed view of pharmaceutical prescribing than the hospital billing system. On a quarterly basis an electronic report is received from two outpatient pharmacies. The data is compared to existing patient information in the claims database and all matching data is merged. The pharmacy information includes detailed charge codes, drug descriptions, CPT codes and quantities of drugs dispensed.

The MCCIS claims database was developed in Foxpro, a PC-based database management system. For increased efficiency related to automated data cleaning and partial processing, scalability, and usability the claims database has been ported to SQLServer, a server-based relational database management system. The structure and content of the information remains the same.

- Pathology Research Data Warehouse

The Pathology Department and Massey Cancer Center have developed an in-house data repository known as the Pathology Research Data Warehouse (PRDW). In its initial conception, it provided a means of automated data aggregation and a platform for analyzing data from multiple hospital data systems to provide a more complete view of cancer patient information that could be used for research purposes. Included in the PRDW are genomics data and tissue specimen data as well as in-depth survey information including health risk behaviors, family history and medical history. These data are linked with hospital-based patient information including demographics, claims and both anatomic and clinical pathology. The PRDW currently is updated on an *ad hoc* basis and is not used directly by the hospital registry.

Related to the PRDW is a smaller ‘shadow’ database that maintains only anatomic pathology reports. The PRDW data aggregation scripts are used to extract all Anatomic Pathology cases from the Cerner PathNet system, and the files are automatically transferred by ftp to a separate database. This database provides a backup source for Anatomic Pathology cases in the event the Cerner system is unavailable. The update process is automated and runs daily.

- Hospital registry software application

The VCU hospital cancer registry utilizes software from Electronic Registry Systems (ERS) for abstracting and reporting. The ERS software has proven to be sufficient for accomplishing a narrowly-defined set of registry needs but, like most commercial software, is not able to be modified to meet changing individual requirements.

The hospital registry software is scheduled to be updated to a CNExT system, published by CNET Solutions, a branch of the non-profit Public Health Institute. The change is

motivated by the cancer center's desire to automate electronic data collection from the existing hospital information systems to be used for casefinding, abstracting and patient follow-up activities and for electronic reporting to the central registry. The CNExT system has some of those capabilities in place and there are plans for customization of the software to enhance and expand on those capabilities.

Virginia Cancer Registry

The Virginia Cancer Registry (VCR) was established in 1990 as the state of Virginia's population-based central cancer registry. As such, VCR collects information on all reportable cancers that occur to Virginia residents. VCR participates in the Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) and is a member of the North American Association of Central Cancer Registries (NAACCR). VCR attempts to meet all NPCR and NAACCR requirements for central registry data quality and completeness.

VCR receives incident cancer case information from over 140 hospitals, clinics, pathology laboratories and physicians throughout the state. The information received can come in one of two formats, electronically or on paper reporting forms. See Figure 1 for an overview. Virginia cancer reporting regulations require that data which are reported electronically conform to NAACCR data file layout formats. From facilities that use commercial cancer database software, data are received electronically as a batch of NAACCR-formatted records. The records are received as a file on a diskette, delivered via the U.S. Postal Service. Approximately sixty reporting sites throughout the state submit completed abstracts to the VCR in electronic form; the records these sites send account for about 90% of initial case reports VCR receives each year. These facilities all have dedicated cancer registries that meet cancer program standards the American College of Surgeons' Commission on Cancer establishes. Facilities that do not have commercial cancer database software or that do not have individual cancer registries report incident cases as hard-copy pages reproduced from patient medical records. VCR requires that reporters use a form VCR provides to report such cases. The VCR staff is responsible for creating the cancer abstract from these paper forms. VCU submits information to the central registry electronically.

VCR receives electronic submissions in the form of a compressed and password-encrypted file. The file is decompressed and unencrypted and the records it contains are stored as a named subsystem on the registry's secure server. Depending on the flow of work, multiple subsystems representing transmissions from several reporting facilities may be merged into a single subsystem. VCR Cancer Surveillance Specialists subject all records in all subsystems to a complete set of automated editing routines. The registry specialists review the results and either accept or reject the data transmission. Acceptable transmissions are further reviewed for correct codes and are then merged into the final repository. Rejected transmissions are returned to the originating facility to correct errors and for re-submission.

VCR utilizes Rocky Mountain Cancer Data Systems software for its registry data management.

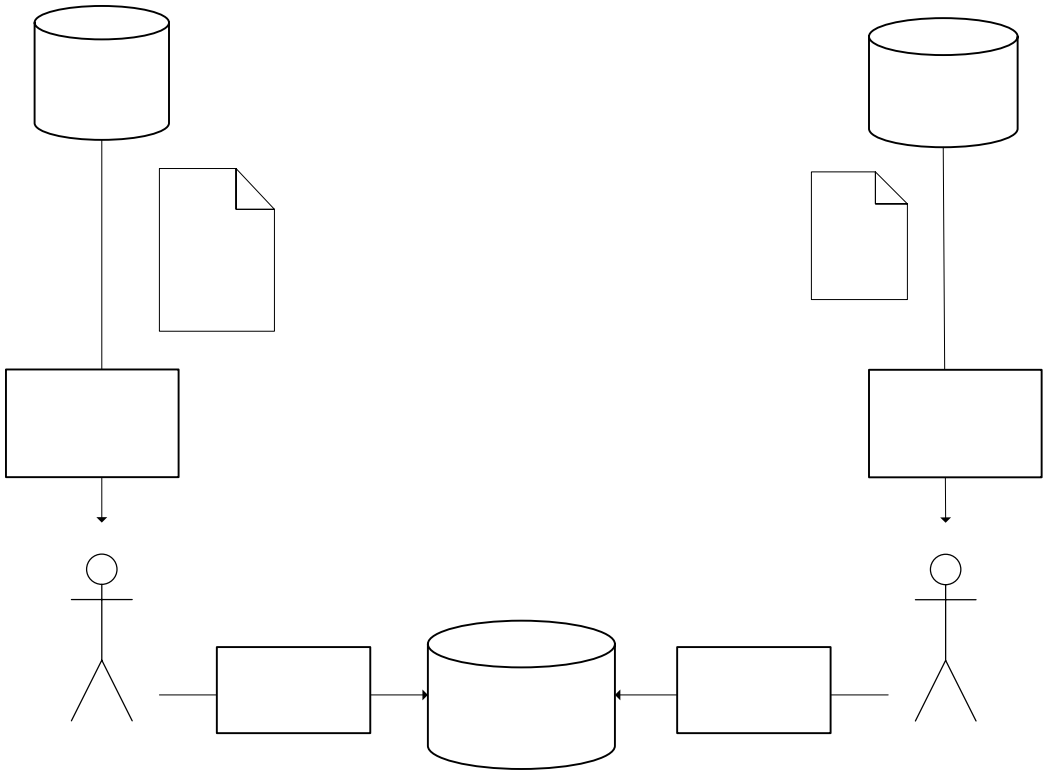

Figure 1. Data Flow Diagram: Current Information Flow into the Virginia Cancer Registry

Electronic Reporting Site

Diskette Containing NAACCR Records

Current Operational Procedures within the Hospital Registry

- Casefinding

The primary source for identifying new cancer cases at VCU is anatomic pathology reports. Twice a week all new pathology reports are sent from the pathology laboratory to the registry in hard-copy form. Both positive and negative reports are received and up to 750 reports per week are manually processed and reviewed. Reports are received within 3-5 days of the pathology report date, and are reviewed within 2-3 days of receipt at the registry. Cancer registrars visually review each individual report, searching for words and terms that indicate a cancer finding. Basic information on new cases is manually transcribed and entered into the registry software application suspense file. If a report identifies a case, an “abstraction file” folder is created that initially contains only the pathology report, but to which other pertinent data will be added as it is identified and downloaded.

A secondary source for casefinding is the MCCIS claims database. As a part of the quarterly reporting that is produced from this database, a report is generated that identifies potential new cancer cases based on any diagnosis reporting a cancer. These are filtered to exclude non-relevant cases or prevalent cases. In practice the majority of these patients will already be present in the registry application, but additional patients may be identified through this approach. The largest proportion of cases identified through this method are non-accessionable cases that are seen for second opinions or treatment of recurrent disease.

- Data collection and abstracting

Within four months of finding a new case, registrars are required, by the American College of Surgeons Commission on Cancer Reporting Guidelines, to complete the cancer abstract. During this time period, registrars collect the additional information related to detailed histopathology and treatment necessary for the abstracting process. All the information is collected as hard copies of reports from the primary hospital data sources.

The Cerner Millennium EMR system is used to access and print additional anatomic pathology results, clinical pathology (clinical lab) results, surgery operative notes, diagnostic procedure reports used in staging such as CT scans, and hospital discharge summaries. The PARS system is used to access and print admission and discharge records, discharge diagnoses as text and ICD-9 codes, and billing records for procedures performed and chemotherapy drugs received. In addition to these reports, the Radiation Oncology department automatically sends copies of treatment notes to the registry on an ongoing basis. The outpatient oncology clinic (Dalton Clinic) sends visit notes automatically or registrars are required to request visit notes from the clinic, depending on the clinic at which the patient is seen.

From the MCCIS claims database quarterly reports of patient treatments are generated for the registry. The reports present information on surgical procedures, radiation treatments and outpatient chemotherapy treatments. The surgical procedure and radiation treatment information is typically also available through the Cerner system and will not always provide new information, but the chemotherapy information is only available to the registry from the claims database and so provides a unique data source. The chemotherapy is derived from detailed billing charges which include information on the chemotherapy agent(s), dose, route and dates of administration.

Once sufficient information has been collected for a given case, the case is transferred from the suspense file to the abstract file within the registry software. All relevant collected information is manually entered into the medical abstract for the case, edits are run to validate the abstract, and the case is marked as ready to be reported to the central registry.

- Patient follow-up status

The American College of Surgeons Commission on Cancer registry guidelines stipulate that every cancer patient should be followed on an annual basis to determine cancer status and survival. Each month the registrar uses the registry software to generate a list of patients who are due for follow-up. This list is created as a spreadsheet, containing patient identifying information (social security number, name, address and phone number).

For each patient in the list, the registrar queries the MCCIS claims database to determine if there is information indicating an inpatient or outpatient hospital visit in the prior 12 months. If a visit is identified, the visit information, including the reason for the visit as reported on the claim, is used to update the case record in the registry software and the patient is removed from the follow-up list. Additionally, contact information for the patient is compared with that in the original file and, if different, that information is updated.

Duplicate patient records are removed from the follow-up list and the list is sent, still as an Excel spreadsheet, to Accurint, an outside vendor that provides a service to locate information on individuals. The vendor returns a report with a status that indicates whether the patient is known to have died and current contact information if it differs from the information that the registry submitted in the original request. The registrar uses the information in this report to update the case records in the registry application. Currently no attempts are made to contact patients who are due or overdue for follow-up as the follow-up rate is high enough to meet registry guidelines. A third alternative to determining patient status is to contact treating physicians. However, because of new privacy regulations, this method is less successful.

- Submission to central registry

The central registry requires the VCU registry to report new and updated cases on a monthly basis. Each month, the registrar runs edits a final time on all cases that are marked as ready for reporting. If errors are discovered at this stage they typically require less than a day to correct. The registry software then generates a report consisting of NAACCR records for all cases that have been marked as ready to report since the last time the report was run. The resulting file is compressed and password-encrypted, copied to a diskette, and mailed to the central registry.

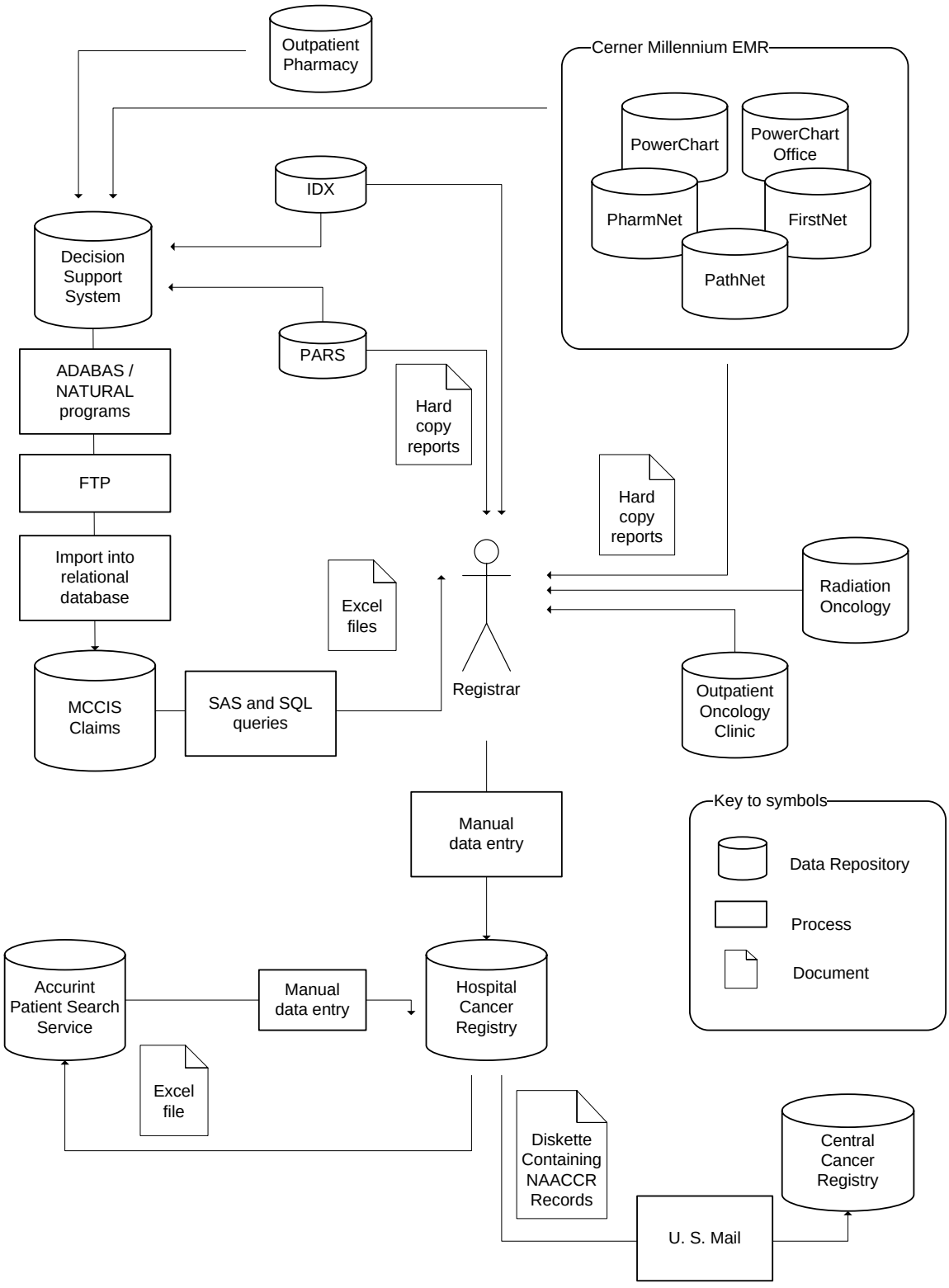

Figure 2. Data Flow Diagram: Current Procedures at VCUHS Cancer Registry

Future plans

The VCU hospital registry intends to implement several significant changes in their system. The goals are to improve casefinding, improve the timeliness of abstracting and reporting and reduce the amount of manual and clerical labor performed by the registrars, allowing them more time to utilize their specialized knowledge and skills.

Casefinding will be performed by the Cancer Alert System (CAS), an ancillary program that will be included with the new registry software (CNExT). The software will receive anatomic pathology reports and discharge records as HL7 formatted messages. These will be generated from the pathology shadow database and claims database, respectively. Accomplishing this will require the implementation and deployment of messaging systems that can access these data sources, construct the appropriate messages, send them, and be able to receive acknowledgments of receipt. Figure 3 provides a view of the data processes involved.

Cancer cases located through this automated approach will likely still require registrar review. Once approved by the registrar, all supporting data included with the messages will be added to the newly created case, reducing the amount of manual data entry, the production of paper copies and handling the copies and reduce the risk of transcription errors thus improving accuracy.

Enhancement of the CNExT capabilities will be undertaken in collaboration with the software vendor. The enhancements will be designed to automate the capture and transfer of additional data to the registry, including clinical pathology data, pharmacy data, medical procedure data and patient follow-up data.

An additional goal of this process will be to provide automated reporting to the central registry. Monthly reports will be transmitted in a PHIN-compliant manner, utilizing security protocols and electronic transmission and eliminating the need for the physical delivery of data.

VCR will develop or make modifications to their existing central registry system to implement a complementary messaging system capable of receiving reports electronically in a PHIN-compliant fashion. Cancer abstract records will be delivered electronically and automatically be merged into the holding subsystem of the cancer registry software system. Central registry registrars will still be responsible for validating incoming records before allowing them to be merged with the main data repository. Figure 4 illustrates the proposed approach.

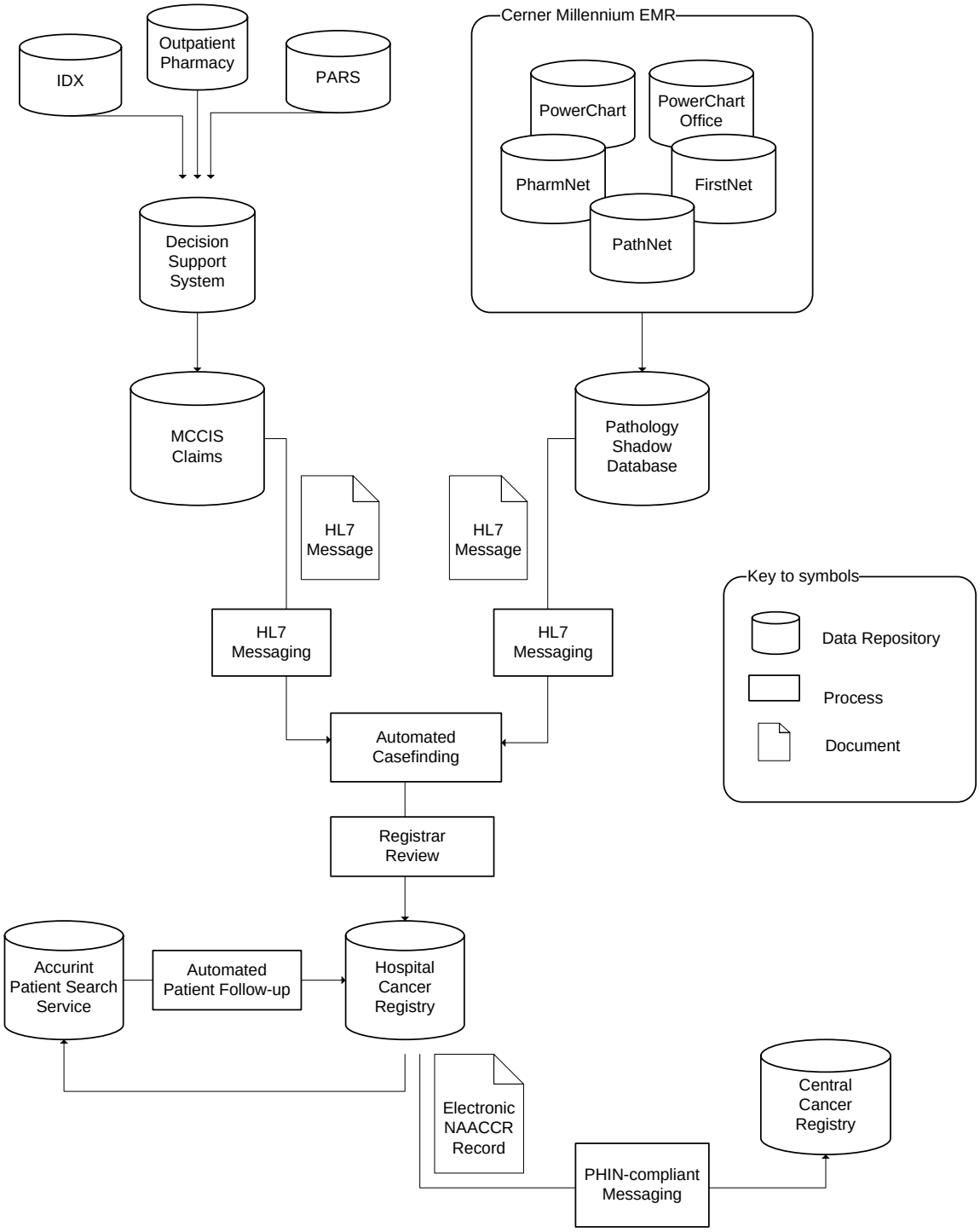

Figure 3. Data Flow Diagram: Proposed Procedures at VCUHS Cancer Registry: Automation of Case Finding, Initial Treatment, Follow-up and Central Registry Reporting

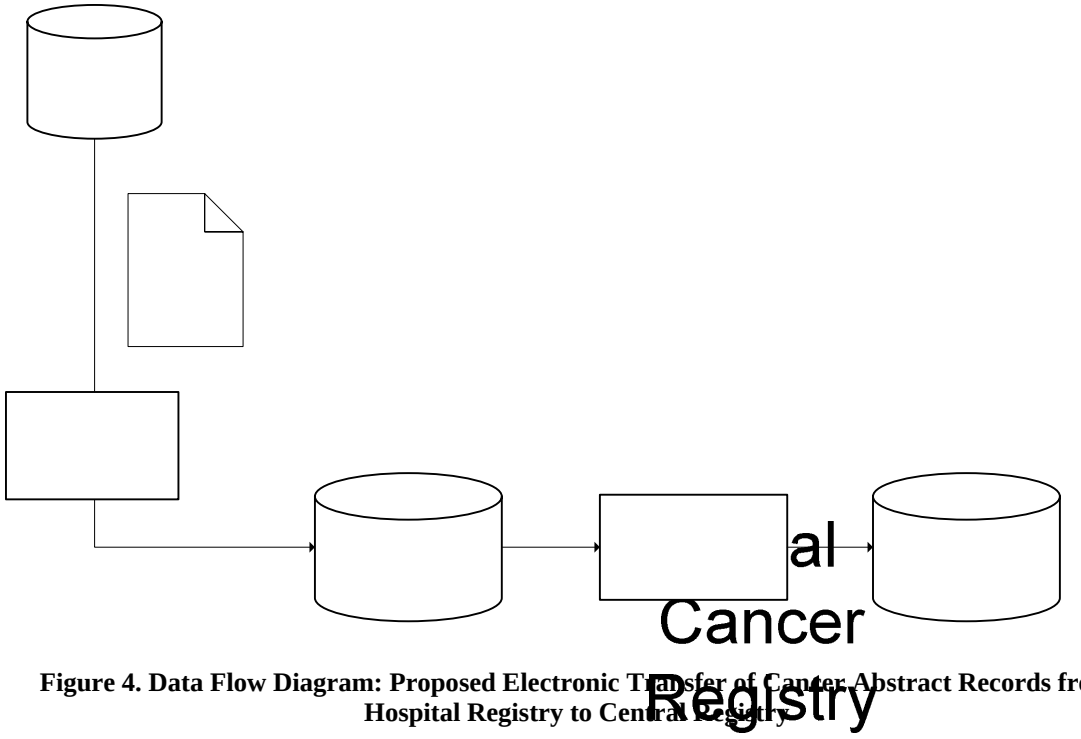

Figure 4. Data Flow Diagram: Proposed Electronic Transfer of Cancer Abstract Records from Hospital Registry to Central Registry

Public Health Information Network (PHIN) Capabilities

The two main PHIN capabilities that are relevant for the current project are messaging and standardized vocabularies. The PHIN messaging standards call for the use of ebXML for message delivery and routing, digital certificates and public key infrastructure (PKI) for message security, and HL7 for message content formatting.

The VCU cancer registry has not had any need to use any of the messaging protocols or techniques in the past and currently has no capacity in place to execute them. It is anticipated that this will soon change. Some standardized vocabulary usage is presently occurring. ICD-9 and CPT codes are used within the MCCIS claims database, and there is an ongoing effort to tag pathology reports with SNOMED codes based on *post hoc* scanning of the narrative reports. The Pathology department is pursuing a project to improve the accuracy of the Cerner automatic SNOMED coding function. If the project is successful, these codes will be an integral part of the pathology reports being sent to the hospital registry.

Electronic
NAACCR
Record

The Virginia Cancer Registry has similarly had no need or opportunity to utilize messaging protocols and currently has no direct capacity for them. The Virginia Department of Health is in the process of implementing the NEDSS Base System (NBS) for reportable disease surveillance, scheduled for early 2005. The NBS implementation will provide some standardized messaging functionality. It is possible that VCR can leverage these resources to incorporate PHIN-compliant messaging in the future.

PHIN-compliant
Messaging

Appendix A. Selected Use Cases

Use Case: Casefinding from Pathology Reports

Primary Actor: Cancer Registrar
Preconditions:
Trigger: a new set of anatomic pathology reports are available for review
Main Scenario:
1. Registrar visually reviews pathology reports to determine if they represent a cancer finding.
2. Registrar identifies a reportable cancer from a pathology report.
3. Registrar enters patient information into 'suspense file' in registry application.
4. Registrar accesses various hospital information systems to gather additional information on patient. Reports are printed and collected in a patient-specific packet.
    - 4.1. Cerner Millennium EMR System
        - clinical pathology results
        - additional anatomic pathology results
        - surgery operative notes
        - other procedural notes, i.e., CT scan notes
        - hospital discharge summaries
    - 4.2. Patient Accounting and Registration System (PARS)
        - admission and discharge records
        - discharge diagnoses, ICD-9 codes
        - billing records for procedures and drugs
    - 4.3. Hardcopy reports, collected and maintained by the registry
        - outpatient oncology clinic notes
        - outpatient radiation oncology treatment notes
5. Case is transferred from suspense file to abstract file and all collected supporting information is entered into registry software system.

Extensions:

Use Case: Determination of Patient Follow-up Status

Primary Actor: Cancer Registrar
Preconditions:
Trigger:
Main Scenario:

1. Registrar uses registry software to generate list of patients whose date of last contact occurred during a given month, typically 12 months ago.
2. For each patient, registrar queries MCCIS claims system to determine if there has been any patient contact during the intervening year, based on the presence of a hospital admission or clinic visit.
    2.1. If yes, the patient's date of last contact is updated in the registry system, and the patient is removed from the list of patients due for follow-up.
3. Duplicate patient records are removed from list.
4. The list is sent to Accurint for processing.
5. Accurint returns a report containing known patient status and current address and phone number, if available.
6. Patient information is updated in registry system if necessary.

Extensions:

Use Case: Case Reporting to Virginia Cancer Registry (VCR)

Primary Actor: Cancer Registrar
Preconditions:
Trigger: Monthly report is due to be sent to central registry
Main Scenario:

1. Registrar uses registry software to generate list of NAACCR records of cases with diagnosis or date of last contact occurring during prior calendar year.
2. Registry software produces a text file.
3. Registrar password-encrypts the file, copies it to a diskette, and mails diskette to VCR.

Extensions:

3a. If the central registry rejects some or all of the records in the report, the local registry is notified, corrections are made locally, and the report is sent again.